

## A World without Down's syndrome

The Government has decided to roll-out a new pre-natal test for Down's syndrome. It has taken its decision without consultation and in the face of widespread concern.

Opposition runs deep. It includes those with the condition and their families but is by no means limited to them. It encompasses all those who are appalled at the prospect of introducing a test to more efficiently eradicate people with Down's.

One of those at the forefront of the opposition is actress Sally Phillips. Perhaps best known for her roles in the Bridget Jones films and BBC's *Miranda*, Phillips is also mum to 11-year-old Ollie, who has Down's syndrome. Her recent BBC documentary 'A World without Down's syndrome?' – made before the Government took its decision – considers what would happen if the new test was made available on the NHS.

The programme was prompted by some stark facts: In England and Wales between 1989 and 2012 almost 20,000 babies were diagnosed in the womb with Down's syndrome. Of these, 92 per cent were aborted<sup>1</sup>. That is nine out of every ten babies diagnosed with Down's syndrome killed in the womb every year – and being classified as a 'severe disability', abortion can take place right up until birth.

The new test – dubbed Non-Invasive Prenatal Testing, or NIPT – is estimated to be more than 98 per cent accurate. The National Institute for Health and Research RAPID evaluation study projects that the proposed implementation will result in 102 more Down's syndrome babies being identified each year<sup>2</sup>. Inevitably, that will mean more Down's babies being aborted. Based on current abortion rates, as many as 92 more *each year* – an increase of 7.5 per cent.

In the documentary Phillips travels from the UK to California via Iceland in an attempt to answer the question 'What's so dreadful about Down's syndrome?' What is it about this condition that strikes such fear into people's hearts that they feel there is no other option but to kill their unborn child? Why does society regard them as such a burden? Along the way she meets parents, scientists and educators and encounters contrasting attitudes towards the sanctity of life.

There is Emma, the mother of a Down's child, who, despite having taken a clear decision not to be tested for the condition when she is pregnant with her second child, has to constantly justify her decision to medical practitioners. And there is Prof. Sue Buckley OBE, a leading expert in education and development for young people with Down's syndrome who, when asked about screening, bluntly states that a diagnosis of Down's syndrome should not be grounds for abortion.

But set against them are some of those who exert considerable influence over Government policy in this area. Key amongst these is Professor Lyn Chitty. It is Chitty who led the NIPT evaluation study and advocates a full roll-out in the NHS, in order to 'better inform' women. Despite the evidence to the contrary, she claims the test it will not significantly affect the current abortion rate.

Phillips also meets Jane Fisher, who runs Antenatal Results and Choices – previously known as Support Around Termination For Abnormality – the only counselling charity the NHS currently directs women to when they get a Down's diagnosis. The actress is visibly disturbed when her hypothetical question about how a learning disability would affect her baby is answered with advice that 'goes straight to termination'. Consider, too, the comments from the Royal College of Obstetricians and Gynaecologists: It has argued that factoring in 'the lifetime costs of caring for children and adults with Down's syndrome' could make the widespread testing 'cost-effective'.<sup>3</sup>

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<sup>1</sup> *The National Down Syndrome Cytogenetic Register for England and Wales: 2013 Annual Report*, December 2014

<sup>2</sup> *RAPID non-invasive prenatal testing (NIPT) evaluation study: a report for the UK National Screening Committee*, May 2015

<sup>3</sup> *Mailonline*, 21 September 2016, <http://www.dailymail.co.uk/news/article-3801102/You-t-price-s-child-s-life-Families-fury-doctors-say-lifetime-cost-care-NHS-justifies-new-simple-blood-test-mothers-be.html>

Phillips struggles to make sense of these and similar assessments just as she struggles in meeting a woman who has opted to abort her baby with Down's syndrome. This is understandable because, as a mother of a lad with the condition, she sees the alternative view as a rejection of her own son.

But there is a different, perhaps deeper, struggle that is apparent in this documentary: Sally Phillips maintains that she is pro-choice but the introspection she displays towards the end of the programme suggests that she recognises her intellectual position is deeply at odds with her own sense of right and wrong. As she confessed to Prof Chitty, whatever the answer to the problem of Olly growing up without her support after she dies 'it is not termination'. Phillips believes very strongly that abortion, at least for Down's children, is wrong. This is rooted in her own experience, and crucially, her belief that Down's people have so much to contribute to society.

But this, in the end, is the problem that the documentary, that otherwise does so well in challenging the ethics of NIPT, fails to address. The value of human life does not lie in its contribution to society at large, or even to the happiness of a particular family. The new NIPT test has its roots in the idea that some people's lives have little or no value and therefore should be screened out from society. This is profoundly wrong. Unborn children are perhaps the most vulnerable people in our world and need to be protected. All human beings are made in the image of God and have a special, intrinsic value regardless of how young or how old, how able-bodied or disabled they might be. This does not apply only to those with Down's syndrome. Neither does it apply only to those whom parent, family or society has deemed 'makes a contribution'. It applies to us all.

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